

Meeting the Information Needs of Patients: Results from a Patient Focus Group

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Changing roles in health care call for patients to share increased responsibility for managing their health. Patients may need additional health-related information to participate more fully in health care decisions. We examined patients' information needs from the perspective of clinicians, educational software vendors, and patients. The most instructive information came directly from patients in focus groups. The participants in our focus groups clearly sought more information about their health than they had received during visits with their physicians. Patients' needs were specific to their individual clinical situation, and timing was critical. Although physicians spend a significant amount of time on patient education during an encounter, patients typically formulate their questions after the encounter. We used the results of focus groups to develop desired characteristics of patient education material that addresses patients' information needs. Providers who understand and address these needs will be in a better position to effectively engage patients' active participation in their health care.

INTRODUCTION

Among the many changes occurring in healthcare is an increasing recognition of the patients' role in their health management. As the notion of shared decision-making between the patient and the provider gains acceptance, the need to understand patients' information needs becomes essential. The literature reports that patients desire more information than they receive^{1,2} and that this need is underestimated by physicians.^{3,4} Furthermore, shared decision-making has been linked to improved outcomes.^{5,6}

The NetReach project is a four-year project designed to address the need for integrated clinical information in diverse ambulatory care settings (primary care internal medicine clinics, specialty care clinics, faculty practice clinics, independent private practices,

and an urban community clinic). The project team assessed clinicians' information needs in several ambulatory-care practice settings, the methods and results of which have been published previously.^{7,8} On average, of the time physicians spent talking to patients during an encounter, 37% of the time was devoted to patient education. Yet, in a recent study of concordance between patients' understanding of the major health problems discussed during an outpatient encounter compared to the physicians' reports of their patients' problems, 68% of the health problems that physicians reported were not on the patients' lists.⁹ Other studies have shown that patients only partially understand, and quickly forget, the instructions and information they receive during an encounter.¹⁰ When patients understand their instructions, they have an increased compliance with the treatment plans.⁶

To ensure that our information solutions address the needs of patients as well as clinicians, we used multiple approaches to assess patients' information needs. We present the results of our needs assessment in this paper.

METHODOLOGY

We explored three perspectives regarding patients' information needs: 1) clinicians' opinion of important characteristics of patient education materials, 2) vendors' rendition of computer-based patient education materials, and 3) patients' expression of their needs for patient education material, as elicited in focus groups.

Patient Education Task Force

To solicit providers' perspective on patient education needs, we formed a task force of representatives from NetReach clinic sites. The patient education task force consisted of one or more clinician

representatives from each NetReach site and a representative from the Galter Health Science Library. The task force members shared their individual experiences with patient education and used an informal consensus development process to develop desired attributes of patient-education materials, from the clinicians' perspective.

Evaluation of Patient Education Software

Based on the desired attributes of patient education materials defined by the patient education task force, a criteria list was developed against which the project team evaluated the suitability of commercial patient education software for the project. Threshold criteria were set to match the project's objectives. To meet the threshold criteria, a software product had to contain material appropriate for common outpatient problems, allow customization by the user, and operate in an Microsoft Windows™ environment.

Patient Focus Groups

We used the focus group technique to get direct feedback from patients on their need for information pertaining to their health. Names and telephone numbers of patients seen in one of five NetReach ambulatory care sites were generated from visit schedules. Fifty names from each site (evenly divided between male and female) were randomly selected. We contracted with an independent market research group to recruit patient volunteers to participate in the focus groups. The market research firm used an interview script to determine participant eligibility. Patients were excluded if they worked in health care or if they had participated in a focus group within the past six months. Eligible patients who agreed to participate were divided into two focus groups. The focus groups were led by a trained facilitator, audiotaped, and observed by project team members behind a one-way mirror. The patients' identities were not revealed. Informed consent was obtained from the participants.

The focus group session time was spent on four general discussion topics: 1) opinions about patient education materials they had received in the past, 2) reactions to sample patient education handouts on two common health issues (lower back pain and asthma in adults), 3) reactions to a summary document about a patient encounter (including the provider's name, patient's vital signs, active medications, medication allergies, new medications prescribed, new lab tests ordered, new consults

requested, graphed lab test results, printed instructions from the visit, and follow-up appointments and phone numbers), and 4) desired attributes of patient education material.

RESULTS

Patient Education Task Force

The patient education task force reviewed the current situation in their various clinics. Although most of the clinics currently stock patient education materials to hand out to their patients, most of the task force members complained that the materials were often outdated, stored in inconvenient areas, very general in nature, costly, and not comprehensive. In one clinic, the materials also had to be available in a foreign language.

Using their collective experiences and reports from the literature, the task force discussed a set of desired characteristics of patient education materials. The task force felt that patient education materials should be comprehensive and tailored to the patient's specific situation as much as possible. They should be up-to-date, easy-to-understand, and written at an appropriate reading level and in an appropriate language. Accessing the materials should be easy and seamless with the process of care.

Evaluation of Patient Education and Software

Using the list of desired attributes, the task force then developed a set of criteria against which to evaluate commercial computer-based products. The task force agreed that the following attributes were important (ranked in order of importance):

- quick to use
- presents material clearly
- contains information on diseases
- provides follow-up instructions
- allows user to add new topics
- allows user to customize content
- written at the 6th grade reading level for ease of understanding
- easy to use
- contains information on preventative medicine topics
- contains information on medications
- contains references for further information
- available in Spanish
- uses graphics

Of the 15 products evaluated, only two met the threshold criteria. Using a scoring system based on the relative importance of the above criteria, one system was selected to undergo a pilot evaluation. All of the available patient education products were standalone products. That is, they were not interfaced to any computer-based patient record (CPR) system. Three clinics volunteered to install the patient education software on computers in their office. One was a general internal medicine clinic, and the other two were specialty clinics. One-on-one training was done with key users of the system with the agreement that they would train the rest of the clinic staff. Training took approximately 30 minutes. About three months after implementation of the software, user input was sought through informal interviews of site participants. The software has been used very little, if at all. The users reported that it took too long to retrieve and print the relevant material using the software and that the material was too general. The low use rates did not allow for detailed feedback about the product by clinicians. The standalone nature of the product was an impediment to its use.

Patient Education Focus Groups

Of the 24 patients who participated in the focus groups, 11 were male and 13 were female. The remainder of the demographics of the two focus groups are summarized as follows:

Marital Status		Patient Type	
Married	9	Internal Med	13
Single/Other	15	Specialty	11
Age Distribution		Education Level	
20-34	9	High School	1
35-49	11	Some College	5
50-64	3	College Grad	11
65+	1	Post College	7

By nature, the results of a focus group study are qualitative. The major themes described below represent a consensus summary developed by the focus group facilitator and the project team members who observed the session behind the one-way mirror.

Patients Seek Information. It was clear from both focus groups that patients want more information about their illness and treatment plan than they typically receive during physician visits. After an outpatient visit, patients sought information from a variety of information sources including friends, relatives, pharmacies, public libraries, and the World Wide Web. They also sought information about possible alternative treatments, particularly when the illness was of a chronic nature (e.g., hypertension, diabetes). The more information the patient understood, the more the patient felt in control of their health. Patients also used the information to explain the outcome of the encounter to their family members or friends.

Custom-Tailored Information. Patients specifically would like information that is tailored to their own situation. Information should be relevant to the patients' diagnoses, treatments, and treatment alternatives. For example, patients with high cholesterol would like to see their cholesterol results and an explanation of how abnormal it is, what the consequences are, and how they can take steps to favorably affect the results. Generic pamphlets may be helpful, but patients do not pay as much attention to them.

Timing of Questions. Patients seek answers to their questions at the time they formulate their questions, which was generally *not* during the encounter. Patients rarely had time to formulate their questions in the exam room during an encounter. Instead, they concentrated on processing the information they were being told about a new diagnosis, a new medication, or a new lab test that was being ordered. Therefore, the relevant time to satisfy patients' need for information was not during the encounter, but rather when they formulated questions after leaving the clinic.

Need for Physician Endorsement. Although there are a variety of sources from which to get information (e.g., drug store, library, magazines), patients prefer to receive material that their physician has endorsed as credible and applicable to their specific problem. Patients would like their physicians to review the material with them directly, even if only briefly. Simply handing the patient the materials was not viewed as an acceptable alternative to a patient-clinician discussion.

Access to More Information. Patients would like their physicians to recommend other sources of

information as well. Journal articles, URL addresses, or resource telephone numbers are all helpful. These resources give patients additional comfort and confidence that they have ways to access information for future questions. Patients also seek ways of learning from other patients with similar medical conditions, such as through support groups or Internet-based discussion groups.

Personal Medical Record. Patients would like to accumulate as much information as possible about their own health and health problems. Some patients had received After Visit Summaries from the EpicCare® system (a computer-based patient record system by Epic Systems Corporation, Madison, WI) and described these handouts as very useful. In fact, some patients who had received After Visit Summaries saved them as their own personal medical record.

Desired Characteristics of Patient Education Materials

Desired characteristics of patient education materials elicited during the brainstorming exercise are summarized below. The patient education materials should:

- be custom-tailored to the patient's situation
- be well organized, concise, and practical
- be printed so that the patient can take the materials with them
- include personal health data as a record of their health
- be reviewed with the patient by the physician
- help them formulate relevant questions
- include follow up references for more information

DISCUSSION

Clinicians spend significant time performing patient education, often without demonstrable benefit to the patient's health outcome. The results of our patient focus groups made it clear that patients have information needs that are not met. In addition, we gained new insight about a significant timing problem that may be an important reason why patient

instructions are often neither understood nor followed. Patients need access to relevant information at the time they formulate their questions about their health, which is not confined to the time they spend face-to-face with the clinician in the exam room. Frequently, the most important time to answer patients' need for information is when they are at home thinking about the encounter (or being questioned by their family) and finding they have additional questions. Although clinicians spend time during the encounter verbally providing instructions and education, the effectiveness of the educational process may be significantly enhanced if the clinician uses the time to review custom-tailored printed material that the patient takes home. The results of our study can help guide the preparation of patient education materials for this use.

It was clear that the patients who participated in the focus groups seek more information about their health and that the information should be tailored to their specific clinical condition. Clinicians must be able to access patient education material as part of their workflow, however, in order for them to distribute the material as a routine part of their practice. Standalone patient education software is not likely to address these requirements well. Hence, patient educational material should be integrated with a CPR system. We suggest that vendors of patient education content material work with CPR systems vendors to integrate their content into CPR systems.

We are using these results to design custom-tailored patient handouts from our computer-based patient record system. We currently use EpicCare® developed by Epic Systems as our CPR system. At the end of each encounter, the system prints out an After Visit Summary™ document. Each customer site configures the information included on the summary. We currently configure our system to print the appointment date, the name and phone number of the provider who saw the patient, the patient's current medications and allergies, the new medications and lab tests that were ordered during the encounter, patient-specific instructions, and relevant educational materials. Based on the results of the focus groups, we are adding results of selected laboratory tests (which may be graphed if appropriate), an explanation of the results, and additional instructions on measures to improve the patient's health outcome. Inclusion of specific references in print or available on the Internet may also be included. We will measure patients' satisfaction with the document and study the impact

of the material on patients' understanding of, retention of, and compliance with the instructions.

The changes in health care present many challenges, but also some new opportunities. As patients are asked to take more responsibility for their health care, their need for specific information about their health will increase. Providers who understand patients' information needs are in a better position to address those needs. Computer-based patient record systems that integrate patient education material can help clinicians provide patients with the right information at the right time to better support patients' decisions regarding their health.

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